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ABSTRACT

Three hundred twenty-nine parents of developmentally disabled children (0 to 21 years old) were surveyed to test the hypothesis that parents who join parent groups are more likely to be white, highly educated, currently married, Republican, and to have higher family incomes than those who do not join parent groups. The survey questionnaire was designed to provide data regarding: the manner in which the parents first discovered their child was developmentally disabled; availablity of extended family and community support networks; the severity of the disability; the manner in which parents secure community services; professionals utilized; attitudes regarding direct services; involvement in children's educational programs and parents' organizations; opinions about public policy; and long term plans and objectives for their children. Findings were grouped according to characteristics of parents and their children, activities of parent group members and reasons for not attending parent group meetings, and differentiating characteristics of group members and nonmembers. Among findings were the following: although the questionnaires were mailed to both parents in two parent families, almost all were completed by mothers; out of a list of seven reasons commonly given for nonattendance at parent groups, the logistical problem of arranging for babysitters or transportation was reported as a barrier far more often than negative feelings about aspects of the meetings themselves; of those parents who identified themselves as group members, their greatest area of group activity was in the core element of a self help group, socializing with new parents; and parents of preschool age children were most likely to have attended more than four meetings per year while parents of 18 to 21 year old children were least likely. In comparing group members with nonmembers, group members tended to be wealthier and older, their children had lower cognitive skills, they relied on the personal support network more often by seeking friend's advice, they confided in professionals more often, and were higher utilizers of speech therapist services. A detailed explanation of variables is appended. (SW)

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DIFFERENTIALS IN CHARACTERISTICS BETWEEN PARENT GROUP MEMBERS AND NON-MEMBERS*

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ABSTRACT

Family demographics, child's characteristics, effect of child on mother, utilization of personal resources and professional sources, and perceptions of unmet community services differentiate parent group members from non-members. Data from a mail survey questionnaire, completed by 330 parents, were analyzed using the discriminant analysis technique. In general, members are older and wealthier, utilize other parents, friends and professionals as confidants more often; perceive a need for more public education, and feel their children have improved their (parents') life skills.

Introduction

Parents' groups have been the single most important factor behind the progress made in recent years in the rights of mentally retarded children. Parents were among the first to sponsor educational programs for their mentally retarded children (see, for example, Matson, 1974; Terese & Owen, 1970). They fought to get the public school districts to accept their children as students. Since 1975 when federal legislation (Public Law 94-142) mandated education for all handicapped children aged three to twenty-one years, parent groups have taken on the role of monitoring the existing educational, residential and vocational programs. With cutbacks in funding for education parents are now involved in battling to keep those program intact.

While the function of advocating for public services is the one most familiar to the general public, parent groups are involved in a host of activities. What are these parent groups? What do these groups do? Are they representative of all parents of mentally retarded children?

The literature on self help/mutual aid groups for parents of disabled children is limited. The literature on parent groups for children with chronic illnesses and their families (Borman, in press) shows that parent groups have been formed around many different kinds of disabling conditions, such as hemophilia (Katz, 1970), physical handicaps (McMichael, 1971), terminally ill children (Patten, 1974), diabetes (David & Frankel, 1970), leukemia (Heffron, Bommelere & Masters, 1973), cancer (Isenberg, 1981), intractable asthma (Liebman, Minuchin & Baker, 1974), and dwarfism (Ablon, 1982). A review of studies of social factors in mental retardation by Rowitz (1974) indicates that the study of family coping patterns within a network of community resources is only beginning to receive attention by

researchers. In Rowitz's review the only reference to self help groups is in the work of Farber (1968). Farber studied 490 families with severely mentally retarded children. He obtained mailing lists from parents groups in the Chicago area. The findings indicate that there is a tendency for parents within the upper, especially middle, socioeconomic ranks to contact parent associations to a greater extent than might be expected on the basis of the actual adult population distribution. His analysis also showed an under-representation of blacks. He concluded that membership in parents associations tended to be a middle class phenomenon and was not representative socioeconomically of the populations of either educable or trainably mentally retarded children. He found the members of parents associations tended to be from white collar rather than blue collar families and to have children under twenty-one.

Another major study in looking at parent groups for parents of children with mental retardation was done by Katz (1961). Katz focused on the organizational development of parents groups and found that

> parents' and relatives' groups arise in response to a complex set of needs, desires and frustrations experienced by active individual parents and relatives, who take the initiative in organizing themselves and others to help deal with their common problems. As the groups develop and organize they look to the organized health and welfare organizations for guidance and help in their specific problem. To the extent that such help is available and accessible, even though it has not been previously tendered by agencies, the parent and relative groups accept the assistance offered and merge their general objectives into the framework of organized community planning and activity, retaining an educational and a group life aspect of their own.

Katz found that individual participants in these parent groups were motivated to be active on behalf of their children and other children who were similarly afflicted. Their important secondary motivation was the parents' belief that there were special values to be found in the activity of the

membership body and that the group was democratically responsive to the needs and desires of its members.

In general, the study of all types of self help groups is a relatively recent research area. Systematic studies of self help groups and their effects on members have been reported in Lieberman and Borman (1976, 1979) and Borman (1975, 1980, 1982). Basically, self help groups are small voluntary gatherings of persons with similar afflictions or concerns who unite due to their common condition. In small group meetings, members share personal experiences, giving and receiving help from persons who are familiar with the emotional as well as the physical aspects of an affliction. Members find out: (1) that they are not alone or unique, (2) that the problems are, to a greater extent than they assumed, solvable, and (3) that hope can be gained through sharing their experiences. Self help groups are essentially voluntary. Members choose to join and leave the group as their needs change.

This paper intends to bridge the gap between research on families of the mentally retarded and research on self help groups. The purpose of this paper is to describe the differences between parents who join groups and those who do not.

It is hypothesized that parents who join parent groups are more likely to be white, highly educated, currently married, Republican, and to have higher family incomes than those who do not join parent groups. Farber (1968) and Katz (1961) found that members of parent groups were highly educated, middle class and upper middle class whites.

It is hypothesized that parents of more severely disabled children will be more likely to join parent groups than those who do not. Farber (1968) found that the severity of the child's disability affected parents'

participation. Parents of more severely disabled children participate to a greater extent than parents of less severely disabled children.

Parents participation in self help groups will be reflected in the effect of the child on the mother. In families where the child creates more stress it is hypothesized that parents will seek out the help of parent groups. It is also hypothesized that mothers in parent groups will be more likely to perceive that their personal skills have improved due to having a mentally retarded child.

Participants in self help groups are more likely to utilize more services than those who do not (Borman, 1982, in press). Therefore it is hypothesized that parent group members will be more likely to utilize more personal resources and professional services than non-group members.

Since self help groups are often involved in both the mutual aid function and education and advocacy function (Pasquale, 1981), it is hypothesized that parent group members will be more likely to perceive unmet service needs in the community than non-members.

Sampling Procedure

The area of Lake County was selected for the research population because: (a) it is geographically compact, it includes urban, suburban and rural populations; (b) it offers a wide variety of services for mentally retarded persons; (c) providers and consumers of services to retarded persons had a history of cooperation with past efforts to secure related information; and (d) the county contains people from a wide range of socio-economic, ethnic and racial backgrounds.

Sampling population is defined as Lake County, Illinois, parents of developmentally disabled children aged 0-21 years who receive services in

Lake County. For our purposes, developmentally disabled was defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of these disorders and whose handicap required more than 50 percent time in a special education program. All children in the study had severe enough forms of mental retardation so that they would not be classified in the mild or educable range.

Data Collection Procedure

We used a computerized review of the literature and open-ended depth interviews with parents to construct a pre-tested 57 page mail survey questionnaire. Structured closed-ended questions were designed to provide data regarding: (a) the manner in which the parents first discovered their child was developmentally disabled; (b) availability of extended family and community support networks; (c) the severity of the disability; (d) the manner in which parents secure community services; (e) professionals utilized; (f) attitudes regarding direct services; (g) involvement in children's educational programs and parents' organizations; (h) opinions about public policy; and (i) long term plans and objectives for their children.

Because of adherence to regulations governing rights of privacy, we sent consent forms to 751 families identified through the educational facilities serving the County. After a follow-up mailing to increase consents, questionnaires were mailed out over a three month period, from mid-March through mid-June, 1978 to 458 families (61.0 percent) who consented to participate. Quality control procedures to insure respondent anonymity were used. A follow-up mailing resulted in a return of 330 completed ques-

tionnaires (43.9 percent of the families identified and contacted, 72.1 percent of the families who consented to participate).

Returned questionnaires were coded and keypunched and a filed defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. We verified the data by eliminating out-of-range errors and by performing a series of contingency checks.

Characteristics of Parents and Their Children

Although the questionnaires were mailed to both parents in two-parent families, almost all were completed by mothers. Of these mothers, 20 percent had not completed high school, 33 percent were high school graduates, 31 percent had some college or special career training, and 16 percent were college graduates. In 1978 dollars, 33 percent had yearly family incomes before taxes of less than $15,000; 39 percent between $15,000 and $25,000; and 28 percent over $25,000. The vast majority (86 percent) were currently married. About half of the mothers (48 percent) were employed outside the home, a group about equally divided between those holding full-time and those holding part-time jobs. Of the sample, 83 percent were white, 11 percent Black, 3 percent Latin-American, and 3 percent Asian or American Indian.

In general, our respondents were fairly representative of the Lake County population in terms of range of social and economic characteristics, except to over-represent minorities, persons with at least high school graduation, and single parent families. Of the children represented in the questionnaire, 21 percent were identified by the parents as mildly retarded, 34 percent as moderately retarded, 20 percent as severely and profoundly

retarded, 12 percent as having cerebral palsy, 4 percent as autistic, and 9 percent as having epilepsy. Of the children, 57 percent were male and 43 percent were female.

Activities of Parent Group Members and Reasons for Not Attending Parent Group Meetings

Utilization of Parent Groups

Of a total of 329 parents, 48.3 percent were currently members of a parent group and 17.1 percent had either previously held or were currently holding an elective or appointed office in such a group.

During the year previous to the survey, 65.2 percent of parents had attended meetings at which other parents of mentally retarded children were present. Those who attended meetings at least once a month represented 17.9 percent of the sample.

Willingness or unwillingness to participate in parents groups raises the question of what barriers to participation exist. Out of a list of seven reasons commonly given for non-attendance (babysitting and transportation problems; disliking parent group meetings in school; disliking parent groups meetings in public places; real decisions are not made in parent group meetings; never talk about my child in meetings; people in charge of meeting don't care about me [respondent]; and do not like the other parents who attend the meetings), the logistical problem of arranging for babysitters or transportation was reported as a barrier far more often (by 32.8 percent of all parents) than negative feelings about aspects of the meetings themselves (by 7 percent to 18 percent of all parents). All seven barriers to participation were analyzed to compare differences between parent group members versus non-members. On all seven items, parent group members were significantly less likely to report any of the items as bar-

riers to participation (Chi Square statistics range from 19.49 to 33.04, 2df, all Ps < .001).

Parent Group Activities

Of those parents who identified themselves as group members (N = 159), their greatest area of group activity (by 59.7 percent of group members) was in the core element of a self-help group, socializing new parents (for example, sharing your own experiences). Group members were next most likely to participate in outreach activities in the community (such as lobbying, fundraising, obtaining media coverage, and presenting educational programs about mental retardation); work with children in their child's educational program (as a volunteer, room mother or aide) and support a network of services for mentally retarded persons (for example, visiting other facilities, sponsoring joint meetings, building a coalition, or acting as a liaison) (by 42.9 percent, 37.7 percent and 31.2 percent of the members, respectively). Group members were least likely to be involved in laying the foundation for new services or programs (for example, organizing a new kind of parent group, a babysitting service, or a recreational program); performing in-house activities (such as office work, building or classroom maintenance, or working on a newsletter) and laying the foundation for new facilities (for example, creating a new school, sheltered workshop or living facility) (by 26.6 percent, 20.8 percent and 20.1 percent of the members, respectively.

Other questions in the survey support the finding that parents are more involved in the mutual aid aspect of the parent groups. For many parents, a natural process begins with the identification of their child as mentally retarded. What starts as self-awareness often grows into group

social action. First comes the sharing of common concerns and information, with 38.8 percent of all parents having participated in meetings to discuss their attitudes and feelings toward their mentally retarded child and 32.1 percent having participated in an educational group dealing with techniques of child rearing and development. Approximately another one-third of the parents have not done so but report a willingness to participate in these group experiences.

Next comes organization to work for expanding and improving community services as well as for the rights and dignity of all retarded persons. Fewer parents have actively taken this next step with 16.2 percent having participated in a governing or advisory board and 12.4 percent having worked with a political advocacy group. There is considerable untapped potential here with approximately one-third of the parents interested in taking this next step into community action.

Characteristics of Parent Group Members

The younger the child, the more likely parents were to have attended more than four meetings in the past year. Parents of pre-school age children (ages 0-5) were most likely to have attended more than four meetings per year (46 percent) while parents of 18-21 year old children were least likely (18 percent). Parents of younger children are both more likely to have participated in group counseling and educational groups, and to be interested in doing so if they have not yet participated. Conversely, parents of older children are less likely to have participated and to plan to do so.

The more severe the disability the more likely parents are to attend meetings often, and to maintain membership in groups or organizations. Parents of mildly retarded children are far more likely never to have

attended meetings (51 percent) and not to have current membership in parent groups or organizations (80 percent). Similarly, the more severe the disability, the more likely parents are to have participated or to want to participate in parent groups.

Parents with higher family incomes are more likely to attend meetings often, maintain current memberships and to become officers. Parents with higher family incomes are also more likely to have participated in parent groups. Parents with lower family incomes are more likely not to have participated, but do want to do so. Family income is not systematically related to unwillingness to participate.

Factor Analysis

Questionnaire items were factor analyzed using the principal factoring with iteration method and varimax orthogonal rotation. Where indicated simple additive indexes were constructed on the basis of the patterning of items identified by the factor analyses. Single questionnaire items and indices used in this paper are explained in Appendix 1. Table 1 lists the variables and provides the group means for each variable for parent group members versus parents who are not members of support groups.

Groups Members and Non-Members-- Differentiating Characteristics

In this section the results of a multi-variate analysis of group members versus non-members are presented. The analysis addresses the following question: "How do parent group members differ from non-members?" Discriminant analysis is a statistical technique that was used to answer this question. The objective of discriminant analysis is to select and test a group of variables that measure characteristics on which two groups

are expected to differ (Klecka, 1975). A step-wise multiple discriminant analysis between the parent group members and non-members was carried out on the variables listed in Table 1.

TABLE 1 ABOUT HERE

Means for the member versus non-member groups on the variables are presented in Table 1. Where the variables are dichotomous, means presented are the proportion of each of the two groups in the reference category. Reviewing group means and proportions enables us to describe the basic differences between the groups before the effects of intercorrelations are taken into account. In the area of demographics, we note that members as compared to non-members have higher family incomes, are more likely to be older, currently married, and white, to have more years of education, and to be affiliated with the Republican political party.

Among child's characteristics, group members' children have lower social and cognitive skills and perceive their communities to be less accepting of their mentally retarded children. Among variables measuring the effect of the child on mother, we find that group members have experienced more stress in raising their mentally retarded children, yet they feel their skills and involvement in political and religious activities has increased.

Among variables measuring parents utilization of personal support networks, group members are more likely to have other parents of mentally retarded children as close friends, to seek advice from friends and other laymen and to utilize paid and unpaid sitters more often than non-members.

Among professional service utilization variables group members are more likely to confide in professionals and seek advice from professionals

when making important decisions about their mentally retarded children. Parent group members are more likely to seek professional counseling and guidance and their children are more likely to utilize a variety of support services: speech therapist, physical therapist, occupational therapist, and recreational therapist. Although not reported in Table 1, there is no difference in the utilization of any medical specialists (such as, pediatricians, cardiologists, dentists, otolaryngologists, ophthalmologists, audiologists, orthodpedists, psychiatrists, obstetricians, orthodontists, oral surgeons and plastic surgeons) or most social service professionals (such as social workers, clinical psychologists, public health nurses, family group, or individual therapist, genetic counselor, vocational counselor, nutritionist, house parents or foster parents, and professional homemaker) indicating that medical and social services are utilized equally by members and non-members alike.

Among variables measuring perceived unmet services in the community, parent group members are more likely to see a need for more community living facilities, nursing homes, church services, social events for the mentally retarded children, community referral sources, public education activities, day care, and home health aides. Although not reported in Table 1, there is no difference in the perception of unmet services for the following: family support services (such as trained babysitters, crisis lines, repsite care services, and parent or family counseling services), educational/diagnostic services (such as early intervention programs, diagnostic services and clinics, and special education programs), living alternatives (such as large residential facilities and foster homes), and local community services (such as architectural adjustments

for facilitating movement of the disabled, reading materials in libraries on mental retardation, and special buses or vans).

This review of the group means suggests that members differ from non-participants in significant ways such as family demographics, child's characteristics, effects of child on mother, utilization of personal resources and professional services, and perception of unmet service needs in the community. Many of these characteristics may be interrelated, however, and a simple comparison of group means does not control for this. If members are truly different from participants, it should be possible to statistically distinguish between the two groups using discriminant analysis.

Discriminant Analysis Results for Members Versus Non-Members

The variables in the discriminant analysis were entered in a forward step-wise order in order to assess the contributions of each variable to differentiate between members and non-members. Table 1 summarizes the results.

After thirteen steps, no more variables had an F-ratio sufficient for entry into the equation. Two of the family demographic variables had statistically significant coefficients indicating that group members are wealthier and older. These findings are similar to Farber (1968) who found that members of parent associations are within the upper socio-economic ranks and Katz (1961) who found the same.

One measure of child's characteristics had a statistically significant coefficient, indicating that group members' children had lower cognitive skills. This finding is similar to Farber's (1968) who found that parents of more severely disabled children were more likely to participate.

One measure of effect of child on mother had a statistically significant coefficient, indicating that group members' felt their skills and religious and political involvement had increased as a result of having a mentally retarded child.

Three measures of personal support network had statistically significant coefficients, indicating that group members had more parents of mentally retarded children as close friends, sought friend's advice when making important decisions for their child, and utilized paid sitters.

Two measures of professional service utilization had statistically significant coefficients, indicating that group members confide in professionals and see speech therapists more often than non-members.

One measure of perceived unmet services in the community had a statistically significant coefficient, indicating that group members perceived a necessity for expanding or offering more public education about mental retardation in their communities.

The statistics at the bottom of Table 1 summarize the degree of differentiation achieved by the discriminant function. These statistics indicate that the function derived from the thirteen variables discriminates somewhat effectively between the two groups. The degree of differentiation is indicated by Wilk's lambda. Wilk's lambda ranges from 1.00 when no differentiation is found between two groups to 0.00 when two groups are totally differentiated. Our finding indicates that there is a significant difference (Λ = .75 with a Chi-Square = 95.01, 13 df, $p < .0001$) though lambda shows that the differentiation between the groups is not great. The square of the canonical correlation (R_c) can be interpreted as the proportion of variance in the discriminant function explained by the groups. The thirteen variables in our discriminant function explain 26 percent of the

variation between group members and non-members. If this discriminant function was used to classify members and non-members, it would have correctly classified 71.43 percent of the sample.

Discussion

Parent group members differ significantly from non-members on a number of variables. We found that group members tend to be wealthier and older. Their children have lower cognitive skills. Mothers who are members experience more improvement in their skills. Members rely on the personal support network more often by seeking friend's advice, using paid babysitters, and having close friends who are also parents of mentally retarded children. They confide in professionals more often and are higher utilizers of speech therapists' services. Finally, members perceive public education as a service needing to be expanded within their community.

It appears that members do not differ significantly from non-members on a number of important factors. It was hypothesized that members would have more stressful family situations. While differences exist in the direction hypothesized, they are not significant. While members utilize some professional services more than non-members overall there are few differences in utilization patterns. Also, while members do identify gaps in the service delivery system in their communities, there are few differences in perceived needs.

The areas where members differentiate most significantly are in their use of personal resources and professionals as confidants. This indicates that members are involved in the group because of the mutual aid aspect and not for advocacy, fundraising or service creation and maintenance. While groups for parents of mentally retarded children become familiar to the public due to their advocacy for public-supported services, it is the members' common interest in mutual support which differentiates them from non-members.

TABLE 1

STANDARDIZED DISCRIMINANT FUNCTION COEFFICIENTS FOR PARENT GROUP MEMBERS VERSUS NON-MEMBERS

	Group Means		
	Members (N = 159)	Non-Members (N = 170)	Standardized Canonical Discriminant Coefficients
Family Demographics			
Family Income	8.34	7.32	-.313***
Race, White	.94	.76	. . .[a]
Mother's Education	3.75	3.24	. . .[a]
Currently Married	.90	.82	. . .[a]
Political Party, Republican	1.99	1.80	-.134
Mother's Age	40.48	37.69	-.397***
Child's Characteristics			
Low Social Skills	29.97	29.12	. . .[a]
Low Cognitive Skills	12.81	10.79	-.317***
Community Acceptance	24.91	26.71	. . .[a]
Effect of Child on Mother			
Mother's Stress	6.37	5.72	. . .[a]
Mother's Skills Improve	10.74	10.06	-.254***
Personal Support Network			
Parents of MR children are close friends	6.89	5.64	-.307***
Friend's Advice	10.23	8.87	-.201*
Seek Advice from Laymen	2.67	2.64	. . .[a]
Unpaid Sitters Used	.75	.59	. . .[a]
Paid Sitters Used	.50	.35	-.209**
Professional Service Utilization			
Confide in Professionals	6.95	6.13	-.215***
Seek Advice of Other Professionals	8.08	7.79	. . .[a]
Parent Counseling and Guidance	.21	.12	-.119
Speech Therapist	.86	.76	-.181**
Physical Therapist	.63	.56	. . .[a]
Occupational Therapist	.33	.19	-.122
Recreational Therapist	.28	.15	. . .[a]

TABLE 1--Continued

	Group Means		
	Members (N = 159)	Non-Members (N = 170)	Standardized Canonical Discriminant Coefficients
Perceived Unmet Services in Community			
Community Living Facility	.85	.73	. . .[a]
Nursing Home	.73	.66	. . .[a]
Church Services	.65	.55	. . .[a]
Social Events	.75	.68	. . .[a]
Community Referral	.92	.84	. . .[a]
Public Education	.95	.85	-.209***
Day Care	.87	.81	. . .[a]
Home Health Aide	.82	.73	. . .[a]
			χ = .75
			R_C = .51

[a]F-ratio insufficient for entry.

* p = .10.
** p = .05.
*** p = .01.

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APPENDIX 1

DETAILED EXPLANATION OF VARIABLES

Family Demographics

Family income is the present (1978) yearly family income before taxes, including dividends, interest, salaries, wages, pensions and all other income. Ten income categories were provided ranging from less than $2,000 to $25,000 and over.

Respondent's race is a dummy variable set equal to 1 if the respondent is white, 0 if otherwise.

Mother's education is the level of formal schooling completed by the respondent measured in terms of seven categories ranging from elementary school or less to advanced post-graduate degree.

Marital status is a dummy variable set equal to 1 if the respondent is currently married, 0 if otherwise.

Political party is the respondents affiliation with political parties, set equal to 1 if Democrat, 2 if Independent, and 3 if Republican.

Mother's age is respondent's age in years.

Child's Characteristics

Low social skills is an index which measures reported level of disabilities on twelve items: diagnosis as mild, moderate, severe, or profound; self care activities (for example, goes to toilet without help, gets dressed, feeds self); understands when spoken to; speaks clearly enough to be understood; organizes activities for self (for example, turns on television, picks up book or magazine, suggests playing a game); self help skills (for example, shops, picks out correct clothing for weather or event, prepares some meals, handles money); shakes hands when meeting someone for the first time; greets people by saying hello; eats properly; speaks at the proper volume; looks at people when spoken to; and knows how to behave properly in different settings. The index has a range of 12 to 60 with a high score representing the lowest level of social skills.

Low cognitive skills is an index which measures the mentally retarded child's reported abilities in the following areas: reads simple sentences, writes simple sentences, and rides public transportation alone. The value for each respondent with the child living at home is obtained by summing the scores on three Likert scale items each ranging from "handles easily" to "child cannot do." The index has a range of 3 to 15.

Community acceptance is an index which measures perceived acceptance by neighbors of the respondent's mentally retarded child at different stages in life in the following situations: as a friend of their own children of the same age; of the opposite sex; as a classmate at the same school; as a member of a social club; as a guest in their own homes; as a neighbor living in a community living facility upon reaching adulthood; and visiting respondents when child is at home. The value for each respondent is obtained by summing scores from seven Likert scale items, giving the index a range of 7 to 35.

Effect of Child on Mother

Mother's stress, or tension experienced by mother, is an index which measures the amount of stress the respondent reports associated with the mentally retarded child. The value of mother's stress for each respondent is obtained by summing responses to three items covering the mother's reports of: becoming so frustrated by the problems caused by the disability that she wished the child would die; feeling trapped at home because of the child; and wishing she could go out more without the child. The value is obtained by summing the scores from three Likert scale attitude questions, giving the index a range of 3 to 15.

Mother's skills improve is an index which measures the amount of improvement the respondent reports as a result of having a mentally retarded child. The value for each respondent is obtained by summing the responses to three items covering the mother's reports of: learning new skills; political involvement; and religious involvement. The index value is obtained by summing the scores from three Likert scale attitude questions, giving the index a range of 3 to 15.

Personal Support Network

Parents of mentally retarded children are close friends is an index which measures respondent's friendship with other parents of mentally retarded children. The value for each respondent is obtained by summing the scores to three separate items: confiding in husband when worried; confiding in other parents with mentally retarded children when worried; and proportion of closest friends who have children with mental retardation. The index has a range of 3 to 15.

Friend's advice is an index which measures frequency of consulting friends and family members for advice about the mentally retarded child. The index value for each respondent is obtained by summing the scores to three Likert scale items: confiding in friends or relatives when worried; talking to other parents of mentally retarded children; and talking to other family members or friends when making a serious decision. The index has a range of 3 to 15.

Seek advice from laymen is an index which measures respondent's reliance upon laymen for advice. The value for each respondent is obtained by summing the scores to two 3-point items: asking for or receiving recommendations from religious leaders; and asking for or receiving recommentations from other parents of mentally retarded children. The index has a range of 2 to 6.

Unpaid sitters used is a dummy variable, set equal to 1 if the parents use unpaid sitters, 0 if otherwise.

Paid sitters is a dummy variable, set equal to 1 if the parents use paid sitters, 0 if otherwise.

Professional Service Utilization

Confide in professional is an index which measures frequency with which respondent consults medical and social service professionals for advice about the mentally retarded child. The value for each respondent

is obtained by summing the scores to two Likert scale items: confiding in the doctor or other medical professional when worried; and confiding in social service professionals when worried. The index has a range of 2 to 10.

Seeking advice of other professionals is an index which measures respondent's choice of counsel when making a serious decision about the mentally retarded child. The value for each respondent is obtained by summing the scores from two items: seeking counsel from child's teacher or principal; and seeking counsel from another school professional. This index has a range of 2 to 10.

Parent counseling and guidance is a dummy variable set equal to 1 if the parents use this service, 0 if otherwise.

Speech therapist is a dummy variable, set equal to 1 if the parents have seen a speech therapist for the child, 0 if otherwise.

Physical therapist is a dummy variable, set equal to 1 if the parents have seen a physical therapist for the child, 0 if otherwise.

Occupational therapist is a dummy variable set equal to 1 if the parents have seen an occupational therapist for their child, 0 if otherwise.

Recreational therapist is a dummy variable set equal to 1 if the parents have seen a recreational therapist for their child, 0 if otherwise.

Perceived Unmet Services in the Community

Community living facility is a dummy variable set equal to 1 if the parents perceive community living facilities as an unmet community need, 0 if otherwise.

Nursing home is a dummy variable set equal to 1 if parents perceive nursing homes to be an unmet service need in the community, 0 if otherwise.

Church services is a dummy variable set equal to 1 if the parents perceive a lack of church services for their mentally retarded children, 0 if otherwise.

Social events is a dummy variable set equal to 1 if parents perceive social events to be an unmet service need for their children, 0 if otherwise.

Community referral is a dummy variable, set equal to 1 if parents perceive a need for more community referral services, 0 if otherwise.

Public education is a dummy variable set equal to 1 if parents perceive a need for more public education in their community, 0 if otherwise.

Day care is a dummy variable set equal to 1 if parents perceive a need for more day care services in the community, 0 if otherwise.

Home health aide is a dummy variable set equal to 1 if parents perceive a need for home health aides in their community, 0 if otherwise.